



A Guide for NEW PARENTS

Resources for new parents of
a child with Down syndrome.

the **up side** of
d**own**s

*Supporting & Celebrating
Down Syndrome in Northeast Ohio*



USOD'S MISSION

To provide support, education and advocacy for people with Down syndrome, their families and communities.

the up side of downs

Supporting & Celebrating
Down Syndrome in Northeast Ohio

Dear Parent,

Twenty years ago, I was pregnant with my second child. We knew that he was going to be a boy and we had already named him Alex. We were so excited because our family, we thought, would be complete. We already had a three year old daughter and now a boy—how perfect!

What we didn't expect, however, was to be told that our baby had Down syndrome. I remember the shock and sadness those first few days after he was born. I was fearful of what the future would hold for Alex and for our family. As I held him I knew though that he was such a sweet and precious little thing and I loved him dearly no matter what.

Well, I cannot even imagine our lives without Alex in them. He has brought so much joy, love, pride and hope into our lives that it is hard to even put into words. When he smiles and laughs, the whole world lights up! He has not only touched our lives, but so many others around him.

A big fear that we had when he was born was how this would affect our daughter. I can tell you that it has affected her, but only in a positive way. She is the most patient and compassionate young adult that I have ever known. She is studying to become an Occupational Therapist and was inspired by her brother to follow this path. I believe that having Alex in her life has been a large part of who she is and who she will become in the future.

Alex enjoys the same things that teens his age do including sports, movies, video games, and girls! He attends regular classes at school and has many friends. He has been on the high school swim team and has made great friends over the years. He is an altar server at our church and really enjoys it!

Alex has been a joy in our lives and our family would not be complete without him. My hope is that your baby will bring you the same love and joy that we have experienced.

Thank you,

Laurie

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Congratulations!

Congratulations on the birth or expected birth of your baby! We understand that your baby may have Down syndrome. You probably have a million questions, concerns and fears right now. That is OK. The most important thing to keep in mind is that this diagnosis is not as “life changing” as the fact that you have a new baby. And in most ways, your baby will be just like other infants. Every baby needs to be fed, held, and most of all, loved.

There will be challenges in raising your child, but there will also be many, many joys. It’s normal to be nervous about what lies ahead, but remember that Down syndrome is a condition your baby has, it is not who your baby is. Now is the time to begin learning all you can about Down syndrome and the local services available to you. This New Parent Guide is a great place to start.



Welcome to Holland

by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It’s like this...

When you’re going to have a baby, it’s like planning a fabulous vacation trip – to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It’s all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, “Welcome to Holland.”

“Holland?!?” you say. “What do you mean Holland?!? I signed up for Italy! I’m supposed to be in Italy. All my life I’ve dreamed of going to Italy.”

But there’s been a change in the flight plan. They’ve landed in Holland and there you must stay.

The important thing is that they haven’t taken you to a horrible, disgusting, filthy

place, full of pestilence, famine and disease. It’s just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It’s just a different place. It’s slower-paced than Italy, less flashy than Italy. But after you’ve been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they’re all bragging about what a wonderful time they had there. And for the rest of your life, you will say “Yes, that’s where I was supposed to go. That’s what I had planned.”

And the pain of that will never, ever go away... because the loss of that dream is a very significant loss.

But... if you spend your life mourning the fact that you didn’t get to Italy, you may never be free to enjoy the very special, the very lovely things... about Holland.



You are not alone

When Parents Learn that their Child has a Disability

By Patricia McGill Smith

If you have recently learned that your child is developmentally delayed or has a disability (which may or may not be completely defined), this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a disability, I was devastated—and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a “black sack” being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as “having a knife stuck” in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

Many things can be done to help yourself through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

Common Reactions

On learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and this enormous challenge. One of the first reactions is denial—“This cannot be happening to me, to my child, to our family.” Denial rapidly merges with anger, which may be directed toward the medical personnel who were involved in providing the information about the child’s problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by the feelings of grief and inexplicable loss that one does not know how to explain or deal with.

Fear is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and some knowledge of the child’s future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: “What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?” Then other questions arise: “Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?”

Other unknowns also inspire fear. Parents fear that the child’s condition will be the very worst it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of persons with disabilities one has known. Sometimes there is guilt over some slight committed years before toward a person with a disability. There is also fear of society’s rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers or sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is guilt—guilt and concern about whether the parents themselves have caused the problem: “Did I do something to cause this? Am I being punished for something I have done? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?” For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertently let her drop and didn’t tell me. Much self-reproach and remorse can stem from questioning the causes of the disability.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, “Why me?” or “Why my child?”, many parents are also saying, “Why has God done this to me?” How often have we raised our eyes to heaven and asked: “What did I ever do to deserve this?” One young mother said, “I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship.”

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child’s disability.

Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child has a disability, yet parents want to feel competent and capable of handling their own life

situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person.

Rejection is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child—a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise, so that they will know that they are not alone. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

Seek the Assistance of Another Parent

There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he made a statement that I have never forgotten: "You may not realize it today, but there may come a time in your life when you will find that having a daughter with a disability is a blessing." I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And he was the father of a boy with mental retardation.

My first recommendation is to try to find another parent of a child with a disability, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent to Parent Programs. The National Information Center for Children and Youth with Disabilities (NICHCY) has listings of parent groups that will reach out and help you. If you cannot find your local parent organization, write to NICHCY to get that local information.

Talk with Your Mate, Family, and Significant Others

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength. Understand that you each approach your roles as parents differently. How you will feel and respond to this new challenge may not be the same. Try to explain to each other how you feel; try to understand when you don't see things the same way.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life—your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

Rely on Positive Sources in Your Life

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another may be a good friend or a counselor. Go to those who have been a strength before in your life. Find the new sources that you need now.

A very fine counselor once gave me a recipe for living through a crisis: “Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day.”

Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel that this might help you, do not be reluctant to seek this avenue of assistance.

Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the “what if’s” and “what then’s” of the future. Even though it may not seem possible, good things will continue to happen each day. Worrying about the future will only deplete your limited resources. You have enough to focus on; get through each day, one step at a time.

Learn the Terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don’t understand, stop the conversation for a minute and ask the person to explain the word.

Seek Information

Some parents seek virtually “tons” of information; others are not so persistent. The important thing is that you request accurate information. Don’t be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child.

Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and to write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers, and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that is given to you. In the future, there will be many uses for information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports, and progress reports. If you are not a naturally organized person, just get a box and throw all the paperwork in it. Then when you really need it, it will be there.

Do Not Be Intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials and, sometimes, because of their professional manner. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is your child, and the situation has a profound effect on your life and on your child’s future. Therefore, it is important that you learn as much as you can about your situation.

Do Not Be Afraid to Show Emotion

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how they are feeling. The strongest fathers of children with disabilities whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.

Learn to Deal with Natural Feelings of Bitterness and Anger

Feelings of bitterness and anger are inevitable when you realize that you must revise the hopes and dreams you originally had for your child. It is very valuable to recognize your anger and to learn to let go of it. You may need outside help to do this. It may not feel like it, but life will get better and the day will come when you will feel positive again. By acknowledging and working through your negative feelings, you will be better equipped to meet new challenges, and bitterness and anger will no longer drain your energies and initiative.

Maintain a Positive Outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is, truly, always a positive side to whatever is occurring. For example, when my child was found to have a disability, one of the other things pointed out to me was that she was a very healthy child. She still is. The fact that she has had no physical impairments has been a great blessing over the years; she has been the healthiest child I have ever raised. Focusing on the positives diminishes the negatives and makes life easier to deal with.

Keep in Touch with Reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are some things that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then set about doing that.

Remember That Time Is on Your Side

Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!



Find Programs for Your Child

Even for those living in isolated areas of the country, assistance is available to help you with whatever problems you are having. NICHCY's State Resource Sheets list contact persons who can help you get started in gaining the information and assistance you need. While finding programs for your child with a disability, keep in mind that programs are also available for the rest of your family.

Take Care of Yourself

In times of stress, each person reacts in his or her own way. A few universal recommendations may help: Get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

Avoid Pity

Self-pity, the experience of pity from others, or pity for your child is actually disabling. Pity is not what is needed. Empathy, which is the ability to feel with another person, is the attitude to be encouraged.

Decide How to Deal With Others

During this period, you may feel saddened by or angry about the way people are reacting to you or your child. Many people's reactions to serious problems are caused by a lack of understanding, simply not knowing what to say, or fear of the unknown. Understand that many people don't know how to behave when they see a child with differences, and they may react inappropriately. Think about and decide how you want to deal with stares or questions. Try not to use too much energy being concerned about people who are not able to respond in ways you might prefer.

Keep Daily Routines as Normal as Possible

My mother once told me, "When a problem arises and you don't know what to do, then you do whatever it was that you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

Remember That This is Your Child

This person is your child, first and foremost. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or in less need of your love and parenting. Love and enjoy your child. The child comes first; the disability comes second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

Recognize That You Are Not Alone

The feeling of isolation at the time of diagnosis is almost universal among parents. In this article, there are many recommendations to help you handle feelings of separateness and isolation. It helps to know that these feelings have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.



Down syndrome occurs when an individual has three, rather than two, copies of the 21st chromosome.

Getting Started

Important Things to Know

Help with Paying Your Medical Bills

Insurance and Medicaid

Chances are you may already have medical insurance or plans to pay for your baby's hospital bill out of your own pocket. Your child may qualify for benefits such as Medicaid or BCMH (Bureau for Children with Medical Handicaps).

The Bureau for Children with Medical Handicaps (BCMh)

BCMh's mission is to assure, through the development and support of high quality, coordinated systems, that children with special health care needs and their families obtain comprehensive care and services that are family centered, community based and culturally sensitive.

Bureau for Children with Medical Handicaps (BCMh) Nursing services

BCMh is a tax-supported program of the Ohio Department of Health that helps children with special health care needs and their families. The program assists families in obtaining services to diagnose a potential handicapping condition (The Diagnostic Program) and assists with ongoing services for children with an eligible medical handicap (The Treatment Program).

BCMh requires that third party resources such as Medicaid or health insurance pay first. The bureau supplements insurance when families have inadequate coverage, such as exclusions for pre-existing conditions or large deductibles. For more information, please visit their website at <http://www.odh.ohio.gov/odhPrograms/cmh/cwmh/bcmh1.aspx>.

Eligibility

For both the diagnostic and treatment programs, children must be under the age of 21, live in Ohio, be a permanent U.S. resident, and be under the care of a BCMH-approved physician. The Diagnostic Program assists families in obtaining an evaluation of a potentially handicapping condition regardless of the family's income. The Treatment Program is for children who have been diagnosed as having an eligible medically handicapping condition. Families must meet financial eligibility guidelines.

Examples of BCMH assisted services:

- Office Visits to Physicians
- X-ray & Lab
- Physical Therapy
- Prescription Medicines
- Dental Care
- Surgery
- Hearing Aids
- Medical Supplies
- Hospitalization
- Public Health Nursing Services
- Home Visits
- Service Coordination
- Health Assessment & Education
- Developmental Screening
- Advocacy & Referral to Appropriate Health Care Providers
- Medical Nutrition Services
- Assessment & Nutrition Counseling
- Special Formula Assistance
- Follow-up & Monitoring
- Referrals to Appropriate Services



To Apply

Families or agencies may apply to BCMH by contacting a public health nurse at their local health department, the child's physician or the BCMH office at the Ohio Department of Health. Parents may call toll free to **1-800 755-GROW (4769)**.

For assistance in Cuyahoga County (except Cleveland and Shaker Heights), call the BCMH nurses at the Cuyahoga County Board of Health at **216-201-2040 ext. 4015**.

In Cleveland and Shaker Heights, call the BCMH nurses at the Visiting Nurse Association at **216-931-1445**.

For other counties in Ohio:

<http://www.odh.ohio.gov/odhPrograms/cmh/cwmh/bcmh1.aspx>

Ohio Medicaid Programs

Ohio Medicaid offers health care programs for children, families and pregnant women with limited income. Once eligible for Medicaid, each child (birth through age 20) will have access to an important group of services known as Healthchek.

What is Medicaid?

Medicaid is a federal program allowing eligible Ohioans with low incomes to receive needed health services. Services available for payment by Medicaid are unique to each state and are approved under what is called a State Plan. Ohio's State Plan covers services such as hospital stays, check-ups for children and for pregnant women, nursing services, medication coverage, and other services for people who are Medicaid eligible. Medicaid does not pay money to you; instead, it pays a provider that delivers healthcare services to you. Each month, you should receive a Medicaid card to show you are covered. To find out more about becoming a Medicaid recipient, contact your local County Board of DODD or your local county Department of Job and Family Services. For more information, go to their website at <http://www.odjfs.state.oh.us/forms/file.asp?id=1483&type=application/pdf>

Healthy Start

Healthy Start (also called SCHIP) is a Medicaid program available to:

Children (younger than age 19) in families with income up to 200% of the federal poverty level.

Pregnant women in families with income up to 200% of the federal poverty level.

Healthy Families

Healthy Families is a Medicaid program available to:

Families with income up to 90% of the federal poverty level. *(Families must include a child younger than age 19).*

WIC

WIC is the Special Supplemental Nutrition Program for Women, Infants, and Children. WIC helps income-eligible pregnant and breastfeeding women, women who recently had a baby, infants, and children up to five years of age who are at health risk due to inadequate nutrition. The program improves pregnancy outcomes by providing or referring to support services necessary for full-term pregnancies; reduces infant mortality by reducing the incidence of low birth weight (infants under 5 ½ pounds are at greater risk of breathing problems, brain injuries and physical abnormalities) and provides infants and children with a healthy start in life by improving poor or inadequate diets.

WIC provides nutrition education, breastfeeding education and support; supplemental, highly nutritious foods such as milk, eggs, cheese, juice, cereal, beans, peanut butter and iron-fortified infant formula; referral to prenatal and pediatric health care and other maternal and child health and human service programs (examples: Head Start, Medicaid and Food Stamps).

Medicaid Waiver Programs in Ohio

Medicaid waivers are programs offered through the Ohio Department of Job and Family Services (ODJFS), the Ohio Department of Developmental Disabilities (DODD), and the Ohio Department of Aging. A Medicaid Waiver is money available to both children and adults which can pay for services for people with developmental disabilities. A waiver can pay for services to keep you in your home so you do not have to move to a long-term care facility or nursing home. Services can be provided in your home or in the community. Both children and adults can be supported by Medicaid Waiver services.

There are many factors that determine a person's eligibility for a waiver, such as the type and extent of their disability, the prognosis, and their financial assets. Once on the waiver, the child will be eligible for Medicaid even though their family's assets are too high. This is called deeming (waiving) the parent's income.

Medicaid usually pays for doctor appointments, hospital expenses, medicine, therapy, and some adaptive equipment. The Medicaid Waiver allows for Medicaid to be used to pay for additional services. The state writes a plan that tells what kind of services will be provided under their Medicaid Waiver program. The federal government has to approve the Medicaid Waiver plan. The Medicaid Waiver program is funded by both state and federal money.

Currently, the waiver program has a waiting list. There are situations, however, that would deem your child a priority and to move him or her to the top of the list. County Boards must follow the legal definition of 'emergency.' This definition, in part, states "...an emergency is any situation that creates for an individual with developmental disabilities a risk of substantial self-harm or substantial harm to others if action isn't taken within 30 days." Examples of situations that may create substantial harm could be:

- Loss of residence;
- Loss of caretaker;
- Abuse, neglect, or exploitation.

***It is important to note that each individual situation is different. If you think you/your family member should be considered an emergency, contact your County Board and present your specific situation.*

'Priority' is also defined in Ohio law. To be considered a 'priority,' a person must meet certain criteria in one of the priority categories. Your County Board will ask you questions to determine whether or not you meet the criteria for any of the categories. If you want further information about these priority categories and the different requirements for each, contact your local County Board.

What Services Are Available Using Waiver Dollars?

Behavioral Support, Community Access, Community Guide, Community Living Support, Community Residential Alternative, Dental Services, Environmental Accessibility Adaptation, Financial Support Services, Professional Therapeutic Services, Respite, Specialized Medical Equipment and Supplies, Support Coordination, Transportation, Vehicle Adaptation.

This is general information about waiver programs in Ohio. You may apply for a waiver at your County Department of Job and Family Services or contact them for more information.

How will I know what to request?

A County Board of DD staff member will ask you and your family questions to help determine your needs. Working with you, the County Board will create the best possible plan to meet your needs. This plan may include waiver and/or other types of services.

What if I am denied a waiver?

You can ask for a state hearing if you disagree with an action or decision on your case or if you think the local agency has not done something it should have. To ask for a state hearing, call the Bureau of State Hearings at **866-635-3748**, or TTY **614-728-2985**.

To learn more about waivers visit the ODDD website www.dodd.ohio.gov

Types of Medicaid Waivers

Ohio offers two different types of waivers for persons with disabilities. Waiver services provide certain Ohio citizens the training and support they need in addition to the Medicaid State Plan services. State Plan services or traditional Medicaid cover things like prescription medication, hospital care, physician visits and other healthcare services.

Level One Waiver (L1 Waiver)

The Level One Waiver covers items like Homemaker/Personal Care, Respite Care, Transportation Services, Emergency Response Systems, Specialized Medical Equipment and Home Modifications, Emergency Assistance, Supported Employment, and Day Habilitation. This waiver pays for up to \$5,000 per year of services, and allows individuals to stay in their own home or the family home and receive services in the community instead of in a facility.

Individual Options Waiver (IO Waiver)

The Individual Options Waiver covers Homemaker/Personal Care, Home Modifications, Transportation, Respite Care, Social Work, Home-Delivered Meals, Nutrition, Interpreter Services, Specialized Adaptive Equipment/Supplies, Supported Employment, and Day Habilitation. This waiver pays for services on an annual basis and allows individuals to stay in their own home or the family home and receive services in the community instead of in a facility. The annual dollar amount of the waiver is based on peoples' individual needs and what county in the state they live in. The IO Waiver can range from \$5,001 to \$147,454.

Ohio Home Care Waiver

The Ohio Home Care Waiver is a type of waiver for individuals with significant medical complications that may require skilled nursing care. The benefit package consists of nursing services, personal care assistance services and/or skilled therapy services plus, one or more waiver specific service such as: home modifications, home delivered meals, adult day health care, respite care, supplemental transportation, adaptive/assistive devices, and emergency response systems. It is designed to meet the needs of consumers eligible for Medicaid who have been assessed to require an intermediate or skilled level of care. Without the services available through the Waiver benefit, these consumers are at risk for hospital or nursing home placement. Consumers approved for the OHC Waiver benefit may receive care and services at home, or they may choose to receive their care in a nursing facility.

Early Intervention Services

Early intervention is one of the most important things you can do to help your child! It is important for you to contact your local Help Me Grow as soon as possible.

Help Me Grow

Help Me Grow is for children and families at risk for developmental delays. It provides direct services to babies and toddlers who are vulnerable because of family or health circumstances. If your baby meets the criteria, Help Me Grow will make sure he receives proper medical care and will assist you in locating community resources. This program will also help you identify present and future needs of your child.

Help Me Grow provides many types of services to infants and toddlers with developmental delays or disabilities and their families. A system of providers work together to provide early identification and family-centered services that ensure your child receives the proper medical care and access to community resources. The program will provide appropriate specialized services and will help you identify present and future needs of your child.

County Boards of Developmental Disabilities (CBDD)

Early Intervention Services from Birth to Age Three

County Boards of CBDD (sometimes called County Boards of Developmental Disabilities) are the largest provider of specialized services in Ohio for infants and toddlers with delays and developmental disabilities. They are affiliated with Help Me Grow.

Specific questions about early intervention services provided by individual county boards can be answered by contacting the local county board of CBDD. An official referral through the county Help Me Grow central coordinating site is needed to determine eligibility for Help Me Grow and early intervention services through the County Board of CBDD or other provider.

For more information about the Help Me Grow referral and eligibility process, contact your local CBDD or County Help Me Grow Intake & Referral system.

Special Education Services for School Age Children

Preschool Special Education for children ages three through five years and Special Education Services for Children and Youth Ages Six through 21 are provided through local school districts, as directed by the Ohio Department of Education. In some counties, preschool or school-age special education may be available at a County Board of DD-operated location.

County Boards of DD may play a supportive role to school districts and families to help facilitate a child's educational services such as assisting with transitions between important stages, providing case management (also known as services and support administration or 'SSA') services, assisting families in accessing Medicaid Waivers and Family Supports Services, and assisting families with identifying and benefiting from appropriate community employment supports. Many CBDD programs offer parent support and education opportunities. Services may continue throughout adulthood, depending on the needs of the individual and their family.

To be eligible for CBDD services other than special education, county boards use either the Children's Ohio Eligibility Determination Instrument (COEDI), for children ages 6 through 15, or the Ohio Eligibility Determination Instrument (OEDI) for children and adults over the age of 15. An individual is eligible if they have a severe, chronic disability that manifests before the age of twenty-two, and meet other criteria, as outlined in the County Board of CBDD administration rule.

Northeast Ohio County Boards of DD

Ashland County Board

1256 Center Street
Ashland, Ohio 44805
Phone: (419) 289-0470
www.ashlandcbdd.org

Ashtabula County Board

2505 South Ridge Road East
Ashtabula, Ohio 44004
Phone: (440) 224-2155 or 224-2156
www.ashtabuladd.org

Cuyahoga County Board

1275 Lakeside Ave.
Cleveland, Ohio 44114
Phone: (216) 241-8230
www.cuyahogabdd.org

Erie County Board

4405 Galloway Road
Sandusky, Ohio 44870
Phone: (419) 626-0208
www.eriecbdd.org

Geauga County Board

8200 Cedar Road
Chesterland, Ohio 44026
Phone: (440) 729-9406
www.geaugadd.org

Holmes County Board

8001 T.R. 574
Holmesville, Ohio 44633
Phone: (330) 674-8045
www.holmesdd.org

Huron County Board

306 South Norwalk Road West
Norwalk, Ohio 44857
Phone: (419) 668-8840
www.hurondd.org

Lake County Board

8121 Deepwood Blvd.
Mentor, Ohio 44060
Phone: (440) 350-5100
www.lakebddd.org

Lorain County Board

1091 Infirmary Road
Elyria, Ohio 44035
Phone: (440) 329-3734
www.murrayridgecenter.org

Medina County Board

4691 Windfall Road
Medina, Ohio 44256
Phone: (330) 725-7751
www.mcbddd.org

Portage County Board

2606 Brady Lake Road
Ravenna, Ohio 44266
Phone: (330) 297-6209
www.portagedd.org

Richland County Board

314 Cleveland Ave,
Mansfield, OH 44902
Phone: (419) 774-4200
www.richlandcountyoh.us

Stark County Board

2950 Whipple Avenue N.W.
Canton, Ohio 44708
Phone: (330) 477-5200
www.starkdd.org

Summit County Board

89 East Howe Road
Tallmadge, Ohio 44278
Phone: (330) 634-8000
www.summitdd.org

Tuscarawas County Board

610 Commercial Ave SW,
New Philadelphia, OH 44663
Phone: (330) 308-7173
www.tuscbddd.org

Wayne County Board

266 Oldman Rd,
Wooster, OH 44691
Phone: (330) 345-6016
www.waynedd.org

Questions and Answers about Down Syndrome

- Down syndrome occurs when an individual has three, rather than two, copies of the 21st chromosome. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome.
- Down syndrome is the most commonly occurring chromosomal condition. One in every 733 babies is born with Down syndrome.
- There are more than 400,000 people living with Down syndrome in the United States.
- Down syndrome occurs in people of all races and economic levels.
- The incidence of births of children with Down syndrome increases with the age of the mother. However, due to higher fertility rates in younger women, 80 percent of children with Down syndrome are born to women under 35 years of age.
- People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, and thyroid conditions. Many of these conditions are now treatable, so most people with Down syndrome lead healthy lives.
- A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. Every person with Down syndrome is a unique individual and may possess these characteristics to different degrees or not at all.
- Life expectancy for people with Down syndrome has increased dramatically in recent decades - from 25 in 1983 to 60 today.
- People with Down syndrome attend school, work, participate in decisions that affect them, and contribute to society in many wonderful ways.
- All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.
- Quality educational programs, a stimulating home environment, good health care, and positive support from family, friends and the community enable people with Down syndrome to develop their full potential and lead fulfilling lives.
- Researchers are making great strides in identifying the genes on Chromosome 21 that cause the characteristics of Down syndrome. Many feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.

What is Down syndrome?

Down syndrome is the most common genetic condition. One in every 733 babies is born with Down syndrome. The most common form of Down syndrome is called Trisomy 21, because it involves an extra copy of the 21st chromosome.

What impact does Down syndrome have on society?

Individuals with Down syndrome are becoming increasingly integrated into society and community organizations, such as school, health care systems, work forces, and social and recreational activities. Individuals with Down syndrome possess varying degrees of intellectual disabilities, from very mild to severe. Most people with Down syndrome have IQs in the mild to moderate range of intellectual disability.

Due to advances in medical technology, individuals with Down syndrome are living longer than ever before. In 1910, children with Down syndrome were expected to survive to age nine. With the discovery of antibiotics, the average survival age increased to 19 or 20. Now, with recent advancements in clinical treatment, most particularly corrective heart surgeries, as many as 80 percent of adults with Down syndrome reach age 60, and many live even longer.

In the United States, approximately 400,000 families have a child with Down syndrome, and about 5,000 babies with Down syndrome are born each year. More and more Americans will interact with individuals with this genetic condition, increasing the need for widespread public education and acceptance.

What is the cause of Down syndrome?

The additional copy of the 21st chromosome which causes Down syndrome can originate from either the father or the mother. Approximately five percent of the cases have been traced to the father.

Who has the highest risk of having a child with Down syndrome?

Down syndrome can occur in people of all races and economic levels. Older women have an increased chance of having a child with Down syndrome. A 35-year-old woman has about a one in 400 chance of conceiving a child with Down syndrome, and this chance increases gradually to one in 110 by age 40. At age 45 the incidence becomes approximately one in 35.

Since many couples are postponing parenting until later in life, the incidence of Down syndrome conceptions is expected to increase. Therefore, genetic counseling for parents is becoming increasingly important. Still, many physicians are not fully informed about advising their patients about the incidences of Down syndrome, advancements in diagnosis, and the protocols for care and treatment of babies born with Down syndrome.



Myths and Truths About Down Syndrome

Myth: Down syndrome is a rare genetic disorder.

Truth: Down syndrome is the most commonly occurring genetic condition. One in every 733 live births is a child with Down syndrome, representing approximately 5,000 births per year in the United States alone. Today, more than 400,000 people in the United States have Down syndrome.

Myth: People with Down syndrome have a short life span.

Truth: Life expectancy for individuals with Down syndrome has increased dramatically in recent years, with the average life expectancy approaching that of peers without Down syndrome.

Myth: Most children with Down syndrome are born to older parents.

Truth: Most children with Down syndrome are born to women younger than 35-years-old simply because younger women have more children. However, the incidence of births of children with Down syndrome increases with the age of the mother.

Myth: People with Down syndrome are severely “retarded.”

Truth: Most people with Down syndrome have IQs that fall in the mild to moderate range of intellectual disability (formerly known as “retardation”). Children with Down syndrome fully participate in public and private educational programs. Educators and researchers are still discovering the full educational potential of people with Down syndrome.

Myth: Most people with Down syndrome are institutionalized.

Truth: Today people with Down syndrome live at home with their families and are active participants in the educational, vocational, social, and recreational activities of the community. They are integrated into the regular education system and take part in sports, camping, music, art programs and all the other activities of their communities. People with Down syndrome are valued members of their families and their communities, contributing to society in a variety of ways.

Myth: Parents will not find community support in bringing up their child with Down syndrome.

Truth: In almost every community of the United States there are parent support groups and other community organizations directly involved in providing services to families of individuals with Down syndrome.

Myth: Children with Down syndrome must be placed in segregated special education programs.

Truth: Children with Down syndrome have been included in regular academic classrooms in schools across the country. In some instances they are integrated into specific courses, while in other situations students are fully included in the regular classroom for all subjects. The current trend in education is for full inclusion in the social and educational life of the community. Increasingly, individuals with Down syndrome graduate from high school with regular diplomas, participate in post-secondary academic and college experiences and, in some cases, receive college degrees.

Myth: Adults with Down syndrome are unemployable.

Truth: Businesses are seeking young adults with Down syndrome for a variety of positions. They are being employed in small- and medium-sized offices: by banks, corporations, nursing homes, hotels and restaurants. They work in the music and entertainment industry, in clerical positions, childcare, the sports field and in the computer industry. People with Down syndrome bring to their jobs enthusiasm, reliability and dedication.

Myth: People with Down syndrome are always happy.

Truth: People with Down syndrome have feelings just like everyone else in the population. They experience the full range of emotions. They respond to positive expressions of friendship and they are hurt and upset by inconsiderate behavior.

Myth: Adults with Down syndrome are unable to form close interpersonal relationships leading to marriage.

Truth: People with Down syndrome date, socialize, form ongoing relationships and marry.

Myth: Down syndrome can never be cured.

Truth: Research on Down syndrome is making great strides in identifying the genes on chromosome 21 that cause the characteristics of Down syndrome. Scientists now feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.

Public Awareness Language Guidelines

It is important to educate others about using inclusive language and proper terminology when referring to Down syndrome. The following guidelines were adapted from the National Down Syndrome Congress (NDSC) website at www.ndsccenter.org.

The correct name of this diagnosis is Down syndrome. There is no apostrophe (Down). The “s” in syndrome is not capitalized (syndrome).

An individual with Down syndrome is an individual first and foremost. The emphasis should be on the person, not the disability. A person with Down syndrome has many other qualities and attributes that can be used to describe them.

Encourage people to use people-first language. “The person with Down syndrome”, not “the Down syndrome person.” A person with Down syndrome is not “a Downs”.

Words can create barriers. Recognize that a child is “a child with Down syndrome,” or that an adult is “an adult with Down syndrome.” Children with Down syndrome grow into adults with Down syndrome; they do not remain eternal children. Adults enjoy activities and companionship with other adults.

It is important to use the correct terminology. A person “has” Down syndrome, rather than “suffers from,” “is a victim of,” “is diseased with” or “afflicted by.”

Each person has his/her own unique strengths, capabilities and talents. Try not to use the clichés that are so common when describing an individual with Down syndrome. To assume all people have the same characteristics or abilities is demeaning. Also, it reinforces the stereotype that “all people with Down syndrome are the same.”

Here are some basic guidelines for using People First Language

1. Put people first, not their disability

- A “person with a disability”, not a “disabled person”
- A “child with autism”, not an “autistic child”

2. Use emotionally neutral expressions

- A person “with” cerebral palsy, not “afflicted with” cerebral palsy
- An individual who had a stroke, not a stroke “victim”
- A person “has” Down syndrome, not “suffers from” Down syndrome

3. Emphasize abilities, not limitations

- A person “uses a wheelchair”, not “wheelchair-bound”
- A child “receives special education services”, not “in special ed”

4. Adopt preferred language

- A “cognitive disability” or “intellectual disability” is preferred over “mentally retarded”
- “Typically developing” or “typical” is preferred over “normal”
- “Accessible” parking space or hotel room is preferred over “handicapped”

**All information on pages 22-27 was taken from the National Down Syndrome Society's website, www.ndss.org.*

DEVELOPMENTAL MILESTONES

Milestone	Range for Children with Down Syndrome	Typical Range
GROSS MOTOR		
Sits Alone	6 - 30 Months	5 - 9 Months
Crawls	8 - 22 Months	6 - 12 Months
Stands	1 - 3.25 Years	8 - 17 Months
Walks Alone	1 - 4 Years	9 - 18 Months
LANGUAGE		
First Word	1 - 4 Years	1 - 3 Years
Two-Word Phrases	2 - 7.5 Years	15 - 32 Months
PERSONAL/SOCIAL		
Responsive Smile	1.5 - 5 Months	1 - 3 Months
Finger Feeds	10 - 24 Months	7 - 14 Months
Drinks From Cup Unassisted	12 - 32 Months	9 - 17 Months
Uses Spoon	13 - 39 Months	12 - 20 Months
Bowel Control	2 -7 Years	16 -42 Months
Dresses Self Unassisted	3.5 -8.5 Years	3.25 - 5 Years



Down syndrome is the most commonly occurring chromosomal condition. One in every 733 babies is born with Down syndrome.

Physical Therapy

Gross Motor Development and Down Syndrome

By Patricia C. Winders, PT, *Senior Physical Therapist, Down Syndrome Specialist, Sie Center for Down Syndrome, The Children's Hospital, Aurora, CO*

What are some of the challenges that babies with Down syndrome face in their gross motor development?

Children with Down syndrome want to do what all children want to do: they want to sit, crawl, walk, explore their environment, and interact with the people around them. To do that, they need to develop their gross motor skills. Because of certain physical characteristics, which include hypotonia (low muscle tone), ligamentous laxity (looseness of the ligaments that causes increased flexibility in the joints), and decreased strength, children with Down syndrome don't develop motor skills in the same way that the typically-developing child does. They find ways to compensate for the differences in their physical make-up, and some of the compensations can lead to long-term complications, such as pain in the feet or the development of an inefficient walking pattern.

The goal of physical therapy for these children is not to accelerate the rate of their development, as is often presumed, but to facilitate the development of optimal movement patterns. This means that over the long term, you want to help the child develop good posture, proper foot alignment, an efficient walking pattern, and a good physical foundation for exercise throughout life.



What do you do in a typical physical therapy session?

First, I observe what skills the child has already mastered on his or her own. Then I determine what the child is ready to learn next. It's critical that we teach children what they're ready to learn within the next month rather than work on something that's too advanced for them.

Once I know what skill the child is ready to learn, I develop a way to teach him that skill. I break the skill down into its component parts, and then I practice the skill with a variety of strategies to test with which method the child is most successful. The strategies are based on the child's learning style and physical make-up.

Lastly and most importantly, I teach the parents how to practice the skill with their child. The parents can practice the skill when the child is feeling rested and strong, and the skills can be incorporated into the daily routine. Through practice and repetition, the child will develop strength and efficiency, leading to mastery of the skill.

You write that children are typically either “motor-driven” or “observers” by nature. How does temperament impact physical therapy?

Temperament is a person's characteristic manner of thinking, behaving and reacting. I look at a child's pattern of thinking, behaving and reacting when learning gross motor skills. It is my observation that children with Down syndrome fall into two basic categories of temperament: motor-driven and observer. Children who are motor-driven tend to be risk-takers. They like to move fast and tolerate new movements and positions. They do not want to stay in one place and dislike being stationary. Children who are observers are more cautious, careful, and want to be in control. They prefer stationary positions and are easily frightened when learning new movements.

When children who are motor-driven are learning how to walk, for example, they will take risks to take independent steps and will be undeterred by frequent falls. Observers will be more cautious and will only risk independent steps when they are sure of their balance.

Understanding your child's temperament and what motivates him will help you be more effective in helping him learn gross motor skills. You will know in advance which activities he is likely to enjoy and which activities he is likely to resist. Knowing this, you can begin with activities he enjoys and only move on to more difficult ones when he is well rested and motivated to learn.



What are some general tips that parents should keep in mind when working with their child on gross motor skills?

The development of gross motor skills is the first learning task that the child with Down syndrome and his parents will face together. This is an opportunity for parents to begin to understand how their child learns. Use these tips as a starting point to begin to explore your child's learning style.

- Determine what motivates your child. Your child is more likely to move when there is something motivating him. For example, he may crawl to get to a favorite toy. When practicing motor skills, your child's success and enjoyment will depend on how you play, what types of toys you use, and where you place them.
- Think how your child thinks. Figure out what gross motor skills your child likes to do and then build on those skills. For example, if your child likes to be on his belly, teach him pivoting, crawling and climbing; if he likes to sit, teach him to move into sitting by himself. Children often are motivated to learn skills in a different order and it is OK to follow your child's lead and work on what he is ready and willing to learn.
- Set your child up to succeed. Practice skills that your child is ready to learn so that he can accomplish them. Practice when he's at his physical best so that he has the energy, concentration and patience to work on new or emerging skills. Know how to position him and use the best motivators. Lastly, know when to quit. A few well-timed moments when your child understands a new skill and succeeds at it are much more valuable than an hour of struggling that leaves both of you frustrated and upset.
- Read your child's cues. Pay attention to how your child is responding to practicing the skills. If it is too hard, make it easier by changing the set-up or giving more support. Practice as long as your child is doing his best. The quality of time you spend practicing gross motor skills is much more important than the quantity.
- Treat it as a game. You really want to think of teaching and practicing a skill as a game. First, introduce the "game" so your child feels and tolerates the movement. Second, help your child become familiar with the game and understand what you want him to do. Third, practice the game together and gradually lessen your support. Fourth, progress toward independence. The ultimate goal is for your child to master the game and be able to do it on his own.

Children with Down syndrome have a unique learning style, and we need to understand and respect it. A psychologist named Jennifer Wishart has written extensively on this subject. She says we "could run the risk of changing slow but willing learners into reluctant, avoidant learners." I really customize the work I do with each child. I make sure the physical therapy sessions provide a pleasant learning environment for children so that they are willing learners, and I encourage parents to do the same at home. If your child feels imposed upon, he or she is just going to find ways to resist and avoid learning.

Resources:

Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals (1997) by Patricia C. Winders. Published by Woodbine House.
www.woodbinehouse.com

"The Goal and Opportunity of Physical Therapy for Children with Down Syndrome." (2001) Down Syndrome Quarterly 6(2), 1-4.
www.denison.edu/dsq

Down Syndrome: The First 18 Months (2003) by Will Schermerhorn.
www.blueberryshoes.com

Reprinted from the National Down Syndrome Society website: www.ndss.org

Occupational Therapy

Occupational Therapy and the Child with Down Syndrome

By Maryanne Bruni, BSc OT(C)

If you are a parent reading this, you likely have a child with Down syndrome, as I do. My intent with this article is to provide you with some information about how an occupational therapist (OT) may be able to help you and your child. Occupational therapists who work with children have education and training in child development, neurology, medical conditions, psychosocial development, and therapeutic techniques. Occupational therapists focus on the child's ability to master skills for independence. This can include:

- self care skills (feeding, dressing, grooming etc.)
- fine and gross motor skills
- skills related to school performance (eg: printing, cutting etc.)
- play and leisure skills

When your child is an infant, your immediate concerns relate to his health and growth, development of the basic motor milestones, social interaction with you and others, interest in things going on around him, and early speech sounds and responses. At this stage an OT may become involved to:

- assist with oral-motor feeding problems (this can also be addressed by Speech Pathologists). Due to hypotonia and weakness of the muscles of the cheeks, tongue and lips, feeding is difficult for some infants with Down syndrome. OTs suggest positioning and feeding techniques, and can be involved in doing feeding studies, if necessary.
- help facilitate motor milestones, particularly for fine motor skills. Occupational therapists and Physical therapists work closely together to help the young child develop gross motor milestones (eg: sitting, crawling, standing, walking). OTs work with the child at this stage to promote arm and hand movements that lay the foundation for later developing fine motor skills. The low muscle tone and loose ligaments at the joints associated with Down syndrome are real challenges to early motor development and occupational therapy can help your child meet those challenges.

When your child is a toddler and preschooler, she will likely have some independent mobility and will be busy exploring her environment. To assist her development you will want to provide her with many opportunities for learning, you will want to encourage the beginning steps in learning to feed and dress herself, you will want her to learn how to play appropriately with toys and interact with other children, you will be encouraging speech and language skills, and you will continue to provide opportunities for refinement of gross motor skills. At this stage an OT may become involved to:

- facilitate the development of fine motor skills. This is an important stage in the development of fine motor skills for children with Down syndrome. Now they will be developing the movements in their hands that will allow them to do many things as they get older, but many children need some therapy input to ensure that these movements do develop. Children do this through play; they open and close things, pick up and release toys of varying sizes and shapes, stack and build, manipulate knobs and buttons, experiment with crayons etc. Your child may face more challenges learning fine motor skills because of low muscle tone, decreased strength and joint ligament laxity.
- help you promote the beginning steps of self help skills. An OT can help parents break down the skills so expectations are appropriate, and can suggest positioning or adaptations that might help the child be more independent. For example, a child may have more success feeding herself with a particular type of spoon and dish.

Then your child enters the school system and the focus of your energies changes somewhat again! You help your child adjust to new routines, you attend school meetings to plan your child's educational program, you focus on speech and communication, you help your child practice fine motor skills for school (such as learning to print), you expect your child to develop more independence in self help activities, and you search out extracurricular activities that will expose your child to a variety of social, physical and learning experiences. At this stage an OT may become involved to:

- facilitate fine motor skill development in the classroom. Many OTs work in the school system and provide programs to help children with Down syndrome learn printing, handwriting, keyboarding, cutting etc. They will also look at physical positioning for optimal performance (eg: desk size etc.) and assist with program adaptations based on the child's physical abilities.
- facilitate self help skills at home and at school. As with all children, our kids with Down syndrome vary in personality, temperament, and motivation to be independent. Some children with Down syndrome have a desire to do things themselves, such as dress and feed themselves. These children may learn these skills by watching others and participating from a young age. Other children may be happy to let others do things for them, and may resist attempts to help them learn these skills. In these cases an OT may be able to help a parent work out these challenges, while helping the child develop better motor skills to be successful in self help skills.
- address any sensory needs your child may have. Sometimes a parent has a concern about things their child does that may relate to the child's sensory development. For example, a child may excessively put toys in her mouth, she may have poor awareness of her body in space, she may squeeze everything too hard or drop things a lot, or she may not tolerate very well some routines like washing and brushing hair. An OT can offer suggestions to help the child and parents deal with these issues.

As parents we must be concerned with the well-being of our child in all respects. We have so many things to think about and keep track of: medical and dental needs, motor and communication needs, educational needs, advocacy, social and behavioral needs : the list seems to go on and on! We need the help of trained professionals to guide us and to work with our children to help them achieve their potential in life. An occupational therapist is one member of the team that we can rely on to provide professional assistance throughout the growth and development of our children. In Canada, occupational therapy services for children with Down syndrome can be accessed through hospitals, home care programs, infant development programs, specialty nursery schools, public schools, and through private therapy services.

(Editor's note: In the US, OT services can be obtained through Early Childhood Intervention programs, public and private schools, and from private therapists.)

Further information about fine motor development can be found in my book "Fine Motor Skills in Children with Down Syndrome", published by Woodbine House (800-843-7323) in 1998.

Reprinted from the National Down Syndrome Society website: www.ndss.org





Speech Therapy

Speech & Language Skills in Infants, Toddlers & Young Children with Down Syndrome

By Libby Kumin, PhD, Professor of Speech-Language Pathology/Audiology, Loyola College

Speech and language present many challenges for children with Down syndrome but there is information that can help infants and toddlers begin learning to communicate, and help young children progress in speech and language. Although most children with Down syndrome learn to speak and will use speech as their primary means of communication, they will understand language and have the desire to communicate well before they are able to speak. Total communication, using sign language, pictures, and/or electronic synthesized speech can serve as a transitional communication system.

Are hearing problems common in children with Down syndrome?

Ear infections occur frequently in infancy and early childhood in all children. But, because of anatomic differences in the ears of children with Down syndrome (narrow and short canals), they are more susceptible to accumulations of fluid behind the eardrum. This is known as Otitis Media with Effusion (OME). These problems result from fluid retention and inflammation in the middle ear; sometimes with infection. The presence of fluid makes it more difficult for the child to hear, resulting in fluctuating conductive hearing loss. Children should be followed by their pediatrician and otolaryngologist (ENT) and visit an audiologist for auditory testing. This testing can be done soon after birth. Hearing testing should also be done every six months until three years of age and annually through age 12 years. Treatment usually involves either an antibiotic regimen or the insertion of tubes to drain the fluid. These recommendations follow the schedule found in the Down Syndrome Medical Interest Group Healthcare Guidelines, available through NDSS.

Cohen, W. et al (1999) Health Care Guidelines for Individuals with Down Syndrome (Down syndrome preventive medical check list). Down Syndrome Medical Interest Group. Down Syndrome Quarterly, 4, 1-26.

What effect does hearing loss have on speech and language development?

Speech and language are learned through hearing, vision and touch. Hearing is very important to speech, and studies have shown that speech and language development are negatively affected by chronic fluid accumulation. Children with Down syndrome often have fluctuating hearing loss due to the frequency of fluid accumulation. When fluid is present, hearing is affected; as fluid drains, hearing improves. When children do not consistently hear well, it is difficult to learn how sounds and events are related, e.g. the ring of the telephone or someone calling you. So, it is important to ensure that your child is hearing well. Pediatricians and otolaryngologists have great success in treating fluid accumulation, but treatment requires close monitoring.

For more information, see: Shott, S. R. (2000). Down syndrome: Common pediatric ear, nose, and throat problems. *Down Syndrome Quarterly*, 5, 1-6.

Shott, S.R., Joseph, A., and Heithaus, D. Hearing loss in children with Down syndrome. *International Journal of Pediatric Otolaryngology* 1:61 (3): 199-205, 2001.

How is feeding related to speech and language?

Speech is a secondary function that uses the same anatomic structures used for feeding and respiration. Low muscle tone (hypotonia) affects feeding and will also affect speech. In feeding, children gain practice with strengthening and coordinating the muscles that will be used for speech. If your child has difficulty feeding, it is important to seek guidance from a feeding specialist, a speech-language pathologist or occupational therapist who has advanced training. Feeding therapy can help strengthen the oral muscles. This can also have a positive effect on speech.

What other skills are related to speech and language development?

Other important pre-speech and pre-language skills are the ability to imitate and echo sounds; turn-taking skills (learned through games such as peek-a-boo); visual skills (looking at the speaker and looking at objects); auditory skills (listening to music and speech for lengthening periods of time, listening to speech sounds); tactile skills (learning about touch, exploring objects in the mouth); oral motor skills (using the tongue, moving lips); and cognitive skills (understanding object permanence, cause and effect relationships). The family can stimulate these pre-speech and language skills at home. Contact Child Find in your area, and ask for speech-language pathology services for your child. The SLP can help you learn the skills that you need to help your child move along the journey to learning language and using speech. For more information, see:

Kumin, L. (2003). *Early communication skills for children with Down syndrome: Guide for parents and teachers*. Bethesda, MD: Woodbine House.



When will my child say his first word?

Children with Down syndrome frequently begin to use single words between the ages of two and three, but the age of the first word varies, and the first true word may not be a spoken word, but it may be a signed word. Most children with Down syndrome communicate from birth through crying, looking and gesturing. They have the desire to communicate and learn that crying or making sounds can affect their environment and bring them help and play and attention. Many children with Down syndrome, by 10-12 months of age, understand the relationship between a word and a concept. However, at that age, the child generally does not have sufficient neurological and motor skills developed to be able to speak. That's why it is important to provide another system so that the child can communicate and learn language before they are able to speak.

What is total communication?

Total communication (TC) is the combined use of signs and gestures with speech to teach language. Total communication provides the child with an output system to communicate when he or she has not yet developed the skills needed for speech. In total communication, the adult uses sign and speech when talking with the child. The child learns signs in conjunction with speech and uses the signs to communicate. Sign language is a transitional system for children with Down syndrome. Other choices for transitional communication systems are pictures used on a communication board or in a communication exchange system, and/or electronic communication systems which use synthesized speech. Most children with Down syndrome are ready to use a language system many months or even several years before they are able to use speech effectively to communicate. Therefore, a transitional communication system such as sign language, pictures or synthesized voice is frequently needed. A speech-language pathologist and/or augmentative communication specialist (AAC) can help design a transitional communication system for your child. Most children with Down syndrome will use speech as their primary system for communication.

What can parents do to help infants and young children learn speech and language?

Parents are the primary communicators interacting with their babies and young children; thus, parents can do a great deal to help their children learn to communicate. Many of the pre-speech and pre-language skills are best learned in the home environment.

- Remember that language is more than spoken words. When you are teaching a word or a concept, focus on conveying meaning to the child through play or through multisensory experiences (hearing, touch, seeing).
- Provide many models. Most children with Down syndrome need many repetitions and experiences to learn a word. Repeat what your child says, and give him a model to help him learn words.
- Use real objects and real situations. When you are teaching a concept, use daily activities and real situations as much as possible. Teach the names of foods as your toddler is eating, names of body parts while you are bathing your child, and concepts such as under, in and on while your child is playing. Communication is part of daily life.
- Read to your child. Help your child learn concepts through reading about them, field trips in the neighborhood and daily experiences.

- Follow your child's lead. If your child shows interest in an object, person or event, provide him or her with the word for that concept. There are many milestones as the child progresses toward using speech. The child responds to a familiar voice, recognizes familiar faces, experiments with many different sounds, produces strings of sounds over and over and makes a sound to mean you (dada, mama). Many children enjoy looking in a mirror, and increase their sound play and babbling when vocalizing in mirrors. Effective ways to work on these skills at home can be learned through early intervention sessions, through books, workshops and speech and language professionals. For more information, see:

Kumin, L. (2003). Early communication skills for children with Down syndrome: Guide for parents and teachers. Bethesda, MD: Woodbine House.

When should speech-language pathology services begin? What is early language intervention?

Speech-language pathology services can begin in infancy. Treatment may involve sound stimulation, language stimulation accompanying play, feeding, oral motor exercises and/or other techniques. It should always include the family as a partner in treatment because the family is the primary teacher of speech and language. Early language intervention (ELI) is the designation given for services provided to infants and toddlers from birth through the end of age two. Speech-pathology services should be part of a comprehensive overall treatment plan for infants and toddlers. It may involve sessions at home or in a center, and may be part of a team approach involving physical, occupational and other therapists working together with the family.

A government-sponsored early intervention program is available in all communities in the United States.. In Ohio, this program is called Help Me Grow. Speech-language and other therapy services are often provided at these programs for eligible children under age three, based on disability and an evaluation. Most children with Down syndrome qualify for speech-language services. After age three, there are continuing services provided by the child's school system. Other speech services are available through community agencies, private practitioners, university clinics, medical centers and other sources.

How do you find a qualified speech-language pathologist?

Qualified SLPs are certified by the American Speech-Language-Hearing Association and licensed by the state. When a professional is certified, they can use CCC-SLP (Certificate of Clinical Competence in Speech-Language Pathology) following their name. This means they have completed a master's degree in an accredited program, have completed required hours of clinical practice internship and passed a national certification examination. If you are receiving services through Child Find (a federal program that identifies the needs of children with disabilities), the health department or school system in your local area, they will have professionals working with them or they can refer you to local professionals. Members of local Down syndrome support groups can often refer you to speech-language pathologists in your area who have experience working with children with Down syndrome.

**Reprinted from the National Down Syndrome Society website: www.ndss.org*



There are
more than
400,000
people
with Down
syndrome in
the United
States.

Feeding the Infant with Down Syndrome

By Rebecca B. Saenz, M.D.

An infant with Down syndrome can be breast-fed. Breast milk is generally easier to digest than formulas of all types. Furthermore, breast-fed infants have fewer upper and lower respiratory infections, as well as a lower incidence of otitis media, atopic diseases and respiratory allergy. Breast feeding also enhances oral motor development, which is the foundation of speech. The psychologic benefit derived from the bonding of mother and infant can be extremely important at a time when, because of the infant's disability, the mother may be questioning her own adequacy. Even if the infant is unable to breast feed directly, expressed breast milk given another way may be beneficial for the child's health and the mother's emotional wellbeing.

Sucking problems related to hypotonia or cardiac defects may make breast feeding initially difficult, particularly in the premature infant. In this situation, the mother can be encouraged to feed the infant expressed milk by other means, such as a nursing supplementary or a bottle, or, occasionally, by gavage (forced feeding, especially through a tube passed into the stomach). After several weeks, the infant's sucking ability often improves, and the infant becomes capable of nursing effectively. A nursing supplement may be used to encourage the infant who has a weak suck.

Occupational therapists, speech therapists, lactation consultants and breastfeeding support groups usually have specific resources for the mothers of infants with Down syndrome. Mothers may find these resources invaluable. If the breastfeeding infant is not gaining enough weight, consideration should be given to partial supplementation with formula or additional expressed breast milk. A nursing supplement may also be used to provide additional caloric intake while the infant continues to breast feed.

Many infants with Down syndrome tend to be "sleepy babies" in the early weeks. Consequently, feeding only on demand may be inadequate for both the caloric and the nutritional needs of the infant and stimulation of the mother's milk supply. In this situation, the infant should be awakened to feed at least every three hours, or every two hours if only breast feeding is being used. The mother may need to pump her breasts to stimulate the production of an adequate supply of milk.

The mother who prefers formula feeding should also be encouraged to awaken her infant at least every three hours to ensure adequate caloric and nutritional intake. Reflux may be reduced by holding the feeding infant in a semi-upright position and keeping the bottle appropriately angled to prevent the swallowing of air.

Unless weight gain is a problem or an infant with Down syndrome has a particular medical disorder, no specific formula is currently recommended. Formula additives or gavage feeding may be necessary in infants with very poor weight gain.

The diet of an infant with Down syndrome should be advanced according to the usual schedule for food groups. However, delayed eruption of teeth may put off the introduction of hard solids. Parents should be reminded that a great deal of patience is required to teach a child with Down syndrome to feed from a spoon and to drink from a cup.

This article was reprinted with the permission of Dr. Rebecca Saenz.

Is it possible to breastfeed my baby who was born with Down syndrome?

How wonderful that you want to give your baby the precious gift of your milk! Babies with Down Syndrome experience special benefits from breastfeeding beyond the many advantages to typical newborns.

- Breast milk provides extra protection against infections and bowel problems, which are more common in babies with Down Syndrome.
- Breastfeeding improves mouth and tongue coordination, giving a child with Down Syndrome a real developmental advantage.
- The act of breastfeeding provides additional stimulation for your baby.
- Breastfeeding promotes closeness between mother and baby, and enhances mothering skills.
- Extra patience and reasonable expectations are critical when breastfeeding a baby with Down Syndrome. Low muscle tone and a weak suck can impede the baby's ability to breastfeed.

Here are a few tips that may help you breastfeed your baby:

- Because babies with Down syndrome are often sleepy and placid, you may need to interest your baby through frequent breast feedings throughout the day, wake him fully before breastfeeding, or provide extra touch and stimulation to keep him alert.
- Pay extra attention to positioning your baby at your breast. Try to keep your baby's body elevated near your breasts with his ear, shoulder and hip in a straight line and use extra pillows for support.
- If gulping and choking are a problem, try positioning your baby so that his neck and throat are slightly higher than your nipple.
- If poor muscle tone makes it difficult for your baby to latch on well, try supporting your baby's chin and jaw while nursing using the "Dancer Hold." (The name of this position was coined by Sarah Coulter Danner, RN, CPNP, CNM, IBCLC and Ed Cerutti, MD. "Dancer" comes from the first letters of their last names (Dan + Cer).) Hold your baby with the arm opposite the breast you'll be offering. Using the hand on the same side as the breast you are offering, cup your breast with your thumb on one side of the breast, palm beneath, index finger pointing outward, and the other three fingers on the other side of the breast. Use your index finger to support your baby's lower jaw while nursing. As your baby's muscle tone improves through breastfeeding and maturity, he will become able to support himself and breastfeed more effectively.

Resources for Additional Information

These publications may be available from your La Leche League Leader or <http://store.lli.org/>.

Breastfeeding a Baby with Down Syndrome.

Provides education and support for the mother who is breastfeeding a baby with Down Syndrome.

Defining Your Own Success: Breastfeeding after Breast Reduction Surgery

By Diana West: This thoroughly researched book has useful information far beyond what its title suggests. It contains extensive information about supplementation as well as increasing milk supply. Some mothers of babies with Down Syndrome will find this very useful.

La Leche League's classic book, *The Womanly Art of Breastfeeding*, has lots of good information on breastfeeding your baby.

Many mothers find it helpful to call a local La Leche League Leader or attend a La Leche League meeting. The support and information of other breastfeeding mothers may make a big difference for you.

Lactation Consultant who has experience with babies with Down syndrome:

Cheryl Devonshire RN, MSN, IBCLC

Cleveland Clinic Hillcrest Hospital

(440) 312-5332

The Oral-Motor Myths of Down Syndrome

By Sara Rosenfeld-Johnson, M.S., CCC-SLP

Published in ADVANCE Magazine August 4, 1997

There is a visual impression that each of us holds in our mind when we think of a child or adult with Down syndrome. As a Speech Pathologist in private practice for twenty-five years and as a continuing education instructor for speech and language pathology classes on Oral-Motor Therapy, I have learned that this impression is a powerful teaching aid. When I teach, I ask the participants to tell me what they consider to be the characteristics of a Down syndrome child, or any low-tone child from an oral-motor point of view; without fail, I get the same responses. Their portrayals have become so predictable I have come to refer to them as the “Myths of Down syndrome”. This is what these professionals see:

Myth #1: A high narrow palatal vault

Myth #2: Tongue protrusion

Myth #3: Mild to moderate conductive hearing loss

Myth #4: Chronic upper respiratory infections

Myth #5: Mouth breathing

Myth #6: Habitual open mouth posture

Myth #7: Child’s tongue is too big for its mouth

These seven structural/functional disorders have been plausibly associated with Down syndrome, so why label them myths? Because the children my associates and I have worked with over the past fifteen years no longer exhibit these characteristics. The therapeutic community has inadvertently allowed these myths to flourish because we didn’t recognize that they could be prevented. These abnormalities emerge in most children by the time they enter early-intervention programs. What has been missing in our treatment that has allowed them to develop? How do we pursue prevention?

A quick review of some oral motor development basics. Children are born with two cranial soft spots. One on the top of the skull at midline and the other under the skull at the midline. Soft spots facilitate the birth process, allowing plates in the skull to overlap, easing the infant’s downward progress. After birth, the plates return to original position, eventually joining between 12 and 18 months of age. When the plates meet at the top of the skull, they take the shape of the brain’s contour, giving us a round-headed shape. In the Down’s population, this closing of plates may not occur until 24 months of age.

The identical closing of plates occurs under the brain in the plates of the hard palate. Just as the brain lends shape to the top of the head, the tongue shapes the palate. During the closing of the palate, if the tongue is not resting habitually inside the mouth, there is nothing to inhibit plate movement toward midline. The result:

Myth #1, a high, narrow palatal vault. Can this be prevented? Let’s return to the infant at birth. What is not commonly known is that even children with severe low tone at birth, including Down syndrome, are

nose breathers. They maintain their tongues in their mouth and upon examination their tongues are not abnormally large. Orally, these children look pretty much like any other infant with the exception that they have a weak suckle. This critical observation draws us to the connection between feeding muscles and muscles of speech.

In quick order, a cascade of events unfolds for these babies with weak suckle. Many mothers tell me they genuinely wanted to breast feed their newborn but were unable because the child had a weak suckle and/or the mother did not produce sufficient milk. Absent a medical problem, the difficulty is often that the child's suckle was not strong enough to stimulate the mammary glands into producing adequate milk flow.

In this scenario mothers are traditionally encouraged by physicians to use a bottle. Bottle feeding is fine, when done therapeutically, but mothers should be given meaningful choices. Further, when bottle feeding is suggested for these infants, the hole in the nipple is often cross-cut or enlarged to make it easier for the infant to suckle. The child is held in the mother's bent elbow and the bottle is held on a diagonal, nipple down. Visualize this - the milk flows easily into the infant's mouth, but what stops the flow, allowing the child to swallow?

Myth #2: Tongue protrusion; Excessive tongue protrusion is a learned behavior that creates a physical manifestation. Keep visualizing this infant with low tone/muscle strength. There is a sphincter muscle at the base of the Eustachian tube whose function is to allow air to enter the middle ear. If weak muscle tone reduces the effectiveness of this sphincter muscle, then in the described feeding position, milk is able to enter the middle ear. The result: chronic otitis media; a primary causative factor in conductive hearing loss.

Myth #3: Fluid build-up in the middle ear, and the resulting infection, circumfuses throughout mucous membranes of the respiratory system and frequently becomes the originator of chronic upper respiratory infections.

Myth #4: The nasal cavity becomes blocked, the child transfers from nose breathing to mouth breathing.

Myth #5: The jaw drops to accommodate the mouth breathing, encouraging a chronic open mouth posture.

Myth #6: Because the tongue is no longer maintained within the closed mouth, the palatal arches have nothing to stop their movement towards midline and we end up with a high, narrow palatal vault, making full circle back to Myth #1. The child's tongue remains flaccid in the open mouth posture, at rest.

Myth #7: Lack of a properly retracted tongue position. This enlarged appearance of the tongue is therefore not genetically coded, but rather the result of a series of care-provider related responses to the very real problem of weak suckle.

Understanding this scenario provides insight into the characteristics seen in these children when speech and language therapists begin to work on correcting their multiple articulation disorders. Addressing the oral muscles/structure from birth offers a more effective, preventative therapy than the wait-and-see approach taken today. These physical features are not predetermined. Our therapeutic goal should be to normalize the oralmotor system through feeding beginning in infancy. In infancy, nutrition is of primary concern. Our job is to balance nutrition, successful feeding and therapy.

Goal one is to change the position in which the child is being fed. Mouths must always be lower than ears to prevent milk flow into Eustachian tubes. The bottle position is altered to introduce the nipple from below the mouth, vertically encouraging a slight chin tuck. In this position the child draws the milk up the nipple predominately with tongue retraction. This position and retractive action prevents milk from flowing freely into the child's mouth. The child no longer needs strong tongue protrusion to enable swallowing. It is also important not to make the hole in the nipple larger. Can children with weak suckle draw the milk into their mouths in this position? Yes, if you don't use standard glass bottles. Bottles with the disposable liners, in either 4-ounce or 8-ounce sizes, can be filled with either pumped breastmilk or any variety of formula, and the air can be forced out causing a vacuum. This type of bottle can then be fed to the child in an upright position. If the child has trouble drawing the milk up because of weak suckle, you can facilitate the draw by pushing gently on the liner. When I have used this technique with even the most severely impaired children, it has been successful. After a week or so you will be able to push less as the muscles will begin to get stronger.

Facilitation is generally eliminated within 3-6 weeks. Breastfeeding mothers follow the same principles. Hold the child in a position where its mouth is lower than its ears. Stimulate the mammary glands while the child is suckling to increase milk flow. This also enables the mother's milk to come in stronger. As the child's suckle strength increases, the need for gland stimulation will be eliminated. A simple change in the position relationship of the child's mouth to the bottle/breast can improve long-term oral-motor skill levels. That one change prevents a series of abnormal compensatory patterns to develop. It is so significant that I have incorporated feeding intervention into the treatment of all my clients with oral-motor issues regardless of age or diagnosis. Even my third-grade "regular" kids who are seeing me for an interdental lisp work on developing muscle strength and tongue retraction through feeding. If Speech and Language Pathologists accept the premise that normal speech is superimposed on normal oral structures and functions, then the call to provide early therapeutic feeding intervention takes on an importance that we must both acknowledge and affect.

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Sara Rosenfeld-Johnson has a website at: www.talktools.net.





Down syndrome
occurs in people
of all races and
economic levels.

Health Care Information for Families of Children with Down Syndrome

The Prenatal Period (the time before birth)

- **Consider testing as desired**

Prenatal testing for genetic conditions is recommended for families who wish information to help them make decisions about a pregnancy. This testing should be done only after information about the tests has been discussed between the doctor and the family, and the family understands the risks and benefits of the testing.

- **Counseling**

If Down syndrome (trisomy 21) or any other chromosome change that causes Down syndrome is found by prenatal testing, the family should receive counseling to explain the issues and provide support for the family.

- **Prenatal heart testing**

Because there is a high risk of heart problems at birth in Down syndrome, echocardiography (an ultrasound picture of the heart) done during the pregnancy can provide information that may be useful for the remainder of the pregnancy and for the delivery. This information may help with decisions such as where to deliver the baby and the medical services needed late in pregnancy or at delivery.



1 Month to 1 Year

- **Regular well-care visits (check-ups)**

While infants with Down syndrome might need multiple special visits to their doctor and specialty physicians, it is very important that they get regular well-care visits (check-ups). These visits will include checking your child's health, giving immunizations (shots), and building the relationships between the doctor and the family. Developing these relationships will help support the medical and other needs of the child and the family.
- **Monitor growth**

It is important to check growth at every visit. Measurements include height, weight, weight for height, and head circumference. Discuss your child's diet, activity level, bowel and urine patterns, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.
- **Immunizations (shots)**

Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.
- **Heart**

If there were any signs of heart disease in the first month of life, heart monitoring is probably already in place. Heart problems could still worsen or new ones could arise. If concerns exist, it is very important to act early. Breathing that is too fast or cyanosis (a bluish color of the skin) are signs for possible concern.
- **Hearing and vision**

Infants with Down syndrome are at risk for eye problems leading to vision loss or ear problems leading to hearing loss. It is important to have both vision and hearing checked by specialists (ophthalmologist and otolaryngologist/ear, nose, and throat doctor or ENT). The eyes should be tested at birth and again at 1 year or sooner if there are concerns. Hearing should be tested at birth and again every 6 months in early childhood to be sure that the baby's hearing is the best possible.
- **Thyroid**

Thyroid hormone levels can be too low in infants and need to be checked (a TSH test). Low thyroid levels can cause a variety of problems that might not be easy to detect without a blood test. A TSH should be obtained at birth and again at age 6 months and 1 year.
- **Stomach or bowel problems (reflux, constipation, blockages)**

Intestinal issues can occur. Spitting up, stomach swelling, or an abnormal stool pattern can be signs that there is an issue.
- **Neck instability**

Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in the use of hands, walking, or bowel or bladder function. If x-rays are done and the results are abnormal, your child may be referred to a spine or neck specialist. It is recommended that the neck be positioned properly for any medical procedures.
- **Developmental services**

Developmental services (for example, early intervention programs) can be of great benefit to the family with a child with Down syndrome. Developmental services can also help arrange for other related services. These services should provide information to your child's doctor to maintain a close working relationship with the doctor and the family.
- **Social support services**

Many families need additional help with the issues that can arise with the care of children with Down syndrome. All families should discuss with their doctor the social services that may be available and their benefits.
- **Recurrence risk counseling**

Families should get counseling about the possible risk of having another child with Down syndrome, if they choose to have

more children. While the risk is usually low, other factors in the family history might be present, so counseling should be done after a complete review of the family history.

1 Year to 5 Years

- **Regular well-care visits (check-ups)**
At the one-year check-up, you should look at the checklists for newborns and infants to be sure everything has been done as recommended. Follow-up on known problems with specialists and be sure that reports are sent to your child's primary doctor.
- **Monitor growth**
It is important to check growth at every visit. Measurements include height, weight, body mass index (BMI), and head circumference. Discuss your child's diet, activity level, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.
- **Immunizations (shots)**
Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.
- **Heart**
The need to see a cardiologist during this age is based on the child's health history and examination. Children with cardiac lesions may need to be monitored even after repair for remaining lesions and development of pulmonary hypertension (high pressure in blood vessels of the lungs).
- **Hearing**
Hearing should be checked every 6 months, with audiogram and tympanometry tests until normal hearing is documented by testing of both ears separately (usually by 4-6 years of age). Children with hearing loss should be referred to an otolaryngologist (ear, nose, and throat doctor or ENT). Higher risks of hearing problems can go with middle ear fluid and ear infections. Treatment of middle ear fluid often includes the use of ear tubes.
- **Vision**
Vision should be checked at each visit to the doctor and with yearly checkups by a pediatric ophthalmologist (special eye doctor) or a general ophthalmologist who is good with children with disabilities. Crossing eyes or blocked tear ducts might be reasons for quicker action. Early use of eye patches, glasses, or both may help to fix eye crossing while lowering the need for surgery and the risk of vision loss.
- **Thyroid**
The thyroid gland is usually normal in babies with Down syndrome. It can stop working normally for half of people with Down syndrome by adulthood. The symptoms of low thyroid can be hard to notice in people with Down syndrome, so a blood test (TSH) is needed every year, or sooner if symptoms change. When there is a problem, treatment is safe and can often be started by your primary doctor.
- **Blood tests**
Tests for low iron or anemia (hemoglobin and other tests if needed) should be done every year.
- **Stomach or bowel problems (diarrhea, constipation)**
Discuss toilet patterns at each visit, especially any ongoing problems with loose stools or constipation. These are common in children with Down syndrome. Some children with Down syndrome have celiac disease, which is a problem with tolerating some grains, including wheat. Testing can help to identify that condition, and may lead to changes in diet. Celiac disease can affect growth, stooling patterns, and behavior. Let your child's doctor know if your child is having:
 - Very loose stools
 - Hard to treat constipation (hard or painful stools)
 - Slow growth/weight loss
 - Belly pain or stomach swelling
 - New or challenging behavior problems

- **Neck instability**
Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in the use of hands, walking, or bowel or bladder function. If x-rays are done, and the results are abnormal, your child may be referred to a spine or neck specialist. Special neck positioning may be needed for some medical procedures. Let your child's doctor know if your child is having:
 - Stiff or sore neck
 - Change in stool or urination pattern
 - Change in walking
 - Change in use of arms or legs
 - Numbness (loss of normal feeling) or tingling in arms or legs
 - Head tilt
- **Sleep issues**
Obstructive sleep apnea is a common problem for people with Down syndrome, especially those with low muscle tone. Some symptoms are obvious (snoring, restless waking at night, daytime sleepiness), but it can be hard to tell just by watching. AAP guidelines recommend that every child with Down syndrome have a sleep study by the age of 4 years. (That testing may be hard to find in some parts of the country.) Treatment can include special breathing equipment or surgery.
- **Skin**
Discuss with your child's doctor if your child has very dry skin or other skin problems.
- **Brain and nervous system**
Discuss with your child's doctor concerns about neurologic problems, such as seizures.
- **Dental**
Delayed and missing teeth are common. Teeth often come in unusual order.
- **New treatments**
Talk to your doctor about any new treatments or medications you may consider.
- **Recurrence risk counseling**
Talk to your doctor about future pregnancy planning and chances of recurrence of Down syndrome and where prenatal diagnosis is available.
- **Developmental services (early intervention)**
Review your child's development with your doctor. Referral to local early intervention services and other options for therapy may be needed. Speech progress can be very delayed in children with Down syndrome, but after some delays, most will learn to talk well. Until speech is easier for your child, he or she might need help finding other ways to communicate, such as using sign language, pictures, reading, or using electronic communication tools. Behavior problems are often linked to problems with communication, but may reflect other issues, including ADHD or autism. Language delays or hidden abuse are more common than autism but may be misdiagnosed. Talk with your doctor about how to explain social safety and "good and bad touch" as your child grows older.



Life expectancy
for people with
Down syndrome
has increased
dramatically
in recent
decades - from
25 in 1983 to
60 today.



HELPING PROVIDE THE BEST FUTURE FOR YOUR CHILD WITH SPECIAL NEEDS

Your child has so many needs. Your time is very precious. You want the best for your child but it's difficult to take that first step and start talking about these issues.

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Special Needs Planning: Information you need to know about Wills, Trusts, Guardianships and the ABLE Act

[www.ndss.org/Advocacy/Legislative-Agenda/
Economic-Self-Sufficiency-Employment/Achieving-a-
Better-Life-Experience-ABLE-Act/Federal-Achieving-
a-Better-of-Life-Experience-ABLE-Act/](http://www.ndss.org/Advocacy/Legislative-Agenda/Economic-Self-Sufficiency-Employment/Achieving-a-Better-Life-Experience-ABLE-Act/Federal-Achieving-a-Better-of-Life-Experience-ABLE-Act/)



People with
Down syndrome
attend school,
work, participate
in decisions that
affect them and
contribute to
society in many
wonderful ways.

Medical/Financial Resources

Supplemental Security Income (SSI) payments for children with disabilities:

SSI makes monthly payments to people with low income and limited resources who are 65 or older, or blind or disabled. A child younger than age 18 can qualify if he or she meets Social Security's definition of disability for children, and if his or her income and resources fall within the eligibility limits. The amount of the SSI payment is different from one state to another because some states add to the SSI payment. Your local Social Security office can tell you more about Ohio's total SSI payment.

SSI rules about income and resources:

To determine eligibility for SSI, the Social Security Administration (SSA) office decides considers your child's income and resources. Income and resources of family members living in your child's household are also considered. These rules apply if your child lives at home. They also apply if he or she is away at school but returns home from time to time and is subject to your control.

If your child's income and resources, or the income and resources of family members living in the child's household, are more than the amount allowed, we will deny the child's application for SSI payments. We limit the monthly SSI payment to \$30 when a child is in a medical facility where health insurance pays for his or her care. Here is a benefits calculator to see if your family qualifies: www.livestrong.com/article/250112-how-to-calculate-a-childs-social-security-disability-benefits/

SSI rules about disability:

- Your child must meet all of the following requirements to be considered disabled and therefore eligible for SSI.
- Your child must not be working and earning over a determined dollar amount, which is adjusted each year. If he or she is working and earning this amount of money, SSA will find that your child is not disabled.
- The child must have a physical or mental condition, or a combination of conditions, that results in "marked and severe functional limitations." This means that the condition(s) must very seriously limit your child's activities.
- The child's condition(s) must have lasted, or be expected to last, at least 12 months; or must be expected to result in death.
- If your child's condition(s) results in "marked and severe functional limitations" for at least 12 continuous months, we will find that your child is disabled. But if it does not result in those limitations, or does not last for at least 12 months, we will find that your child is not disabled.

Providing information about your child's condition:

When you apply for benefits for your child, we will ask you for detailed information about the child's medical condition and how it affects his or her ability to function on a daily basis. We also will ask you to give permission for the doctors, teachers, therapists and other professionals who have information about your child's condition to send the information to us. If you have any of your child's medical or school records, please bring them with you. This will help speed up the decision on your application.

What happens next?

We send all of the information you give us to the Disability Determination Services in your state. Doctors and other trained staff in that state agency will review the information, and will request your child's medical and school records, and any other information needed to decide if your child is disabled. If the state agency cannot make a disability decision using only the medical information, school records and other facts they have, they may ask you to take your child for a medical examination or test. We will pay for the exam or test. We may make immediate SSI payments to your child. It can take three to five months for the state agency to decide if your child is disabled. However, for some medical conditions, we make SSI payments right away and for up to six months while the state agency decides if your child is disabled.

Following are some conditions that may qualify:

- HIV infection
- Total blindness
- Total deafness
- Cerebral palsy
- Down syndrome
- Muscular dystrophy
- Severe mental retardation (child age 7 or older)
- Birth weight below 2 pounds, 10 ounces

If your child has one of the qualifying conditions, he or she will get SSI payments right away. However, the state agency may finally decide that your child's disability is not severe enough for SSI. If that happens, you will not have to pay back the SSI payments that your child got.

SSI disability reviews:

Once your child starts receiving SSI, the law requires that we review your child's medical condition from time to time to verify that he or she is still disabled. This review must be done:

- At least every three years for children younger than age 18 whose conditions are expected to improve; and
- By age 1 for babies who are getting SSI payments because of their low birth weight, unless we determine their medical condition is not expected to improve by their first birthday and we schedule the review for a later date.

We may perform a disability review even if your child's condition is not expected to improve. When we do a review, you must present evidence that your child is and has been receiving treatment that is considered medically necessary for your child's medical condition.

What happens when your child turns age 18:

- For disability purposes in the SSI program, a child becomes an adult at age 18, and we use different medical and non-medical rules when deciding if an adult can get SSI disability payments. For example, we do not count the income and resources of family members when deciding whether an adult meets the financial limits for SSI. We count only the adult's income and resources. We also use the disability rules for adults when deciding whether an adult is disabled.
- If your child is already receiving SSI payments, we must review the child's medical condition when he or she turns age 18. We usually do this review during the one-year period that begins on your child's 18th birthday. We will use the adult disability rules to decide whether your 18-year-old is disabled.
- If your child was not eligible for SSI before his or her 18th birthday because you and your spouse had too much income or resources, he or she may become eligible for SSI at age 18.

How can I get ready for the disability interview?

- Request a disability starter kit from the social security website or local office. It includes a checklist and a worksheet to help you gather the information you need. Have this information with you at the time of the interview.
- If you have access to the Internet, you can complete an online Child Disability Report at www.socialsecurity.gov/childdisabilityreport.
- For more information, visit our website at www.socialsecurity.gov/disability/ or call toll-free 1-800-772-1213 (for the deaf or hard of hearing, call TTY 1-800-325-0778).

Early Intervention/Help Me Grow

The state of Ohio's Early Intervention services program is called Help Me Grow. It is designed to meet the developmental needs of each child eligible for Early Intervention, and the needs of the family related to enhancing the child's development. In addition to the services below Early Intervention also provides early identification, screening and assessment services.

The following are types of Early Intervention Services:

1. Assistive Technology Device and assistive technology services means any items, equipment, product or system used to increase, maintain, or improve the functional capabilities of children with disabilities, along with the services necessary to use them.
2. Audiology means providing services for children with auditory impairment; determining the range, nature, and degree of hearing loss; and auditory training, aural rehabilitation, speech, reading and listening device orientation and training.
3. Family Training, Counseling and Home Visits means services provided, as appropriate, by social workers, psychologists, and other qualified personnel to assist the family of an eligible child in understanding the special needs of the child and enhancing the child's development.
4. Health Services necessary to enable the infant or toddler to benefit from the other Early Intervention Services.
5. Medical Services only for diagnostic or evaluation purposes means services provided by a licensed physician to determine a child's developmental status and need for Early Intervention Services.
6. Nursing Services includes assessment of health status for the purpose of providing nursing services, provision of nursing care to prevent health problems, restore or improve functioning and promote optimal health and development.
7. Nutrition Services includes assessment and development of appropriate plans to address nutritional needs of children and making referrals to appropriate community agencies.
8. Occupational Therapy includes services to help the child develop and improve self-help skills and adaptive behavior and play. The occupational therapist also addresses the young child's motor, sensory, and postural development.
9. Physical Therapy is designed to prevent or alleviate movement dysfunction through a program tailored to the individual child.
10. Psychological Services address issues related to learning, mental health, and development.
11. Service Coordination means the activities carried out by a service coordinator to assist and enable a child and his family to receive the rights, procedural safeguards, and services.
12. Social Work Services includes assessment, individual and family group counseling and coordination of community resources.
13. Special Instruction includes the design of learning environments and activities that promote the child's acquisition of skills in a variety of developmental areas.
14. Speech-Language Pathology includes identification of children with disorders or delays in communication skills, referrals for medical or other professional services and provision of services. Also includes sign language and cued- language services where necessary.
15. Transportation and related costs necessary for an infant or toddler and the infant's or toddler's family to receive a service.
16. Vision Services means evaluation and assessment of visual functioning, referral for medical or other professional services, and communication skills training.

Other Services means services the Individualized Family Service Plan (IFSP) team deems necessary.

